

Clerk to MAT'S
Blythswood House
West Regent Street
Glasgow G2

20th October, 1992

Dear Sir/Madam,

As you are aware this charity is self supporting: we receive very little financial support from local authorities and none whatsoever at national level. We have to raise donations from the members in order to survive, which we manage only with great difficulty. Our voluntary workers are mainly victims of asbestos, with some support from sympathetic non-victims. All of these workers are wholly voluntary: no one receives any wage and no one receives expenses beyond the barest minimum to cover travelling costs.

We feel we must stress this point since, with respect, neither the Social Works Department nor the DSS, MAT and SSAT services appear able to appreciate the reality of an operation based solely on a voluntary workforce who not only receive no payment but have no working experience in any capacity related to the day-to-day counselling and welfare support operations of the group.

Our workload is heavy. The MAT service will be aware that sometimes we undertake as many as 5 or more Tribunals in one week. Besides this we have other welfare support, counselling and campaigning work. There is a high degree of knowledge and skill required to represent victims at MAT's and SSAT's, and other related welfare rights work. Within Clydeside Action on Asbestos we have had only two voluntary workers capable of performing these services. Neither is able to continue the work; there is no one else available with the requisite expertise.

We draw our voluntary victim workers from our own members. But our own members die on an average of 3 to 4 people per month from asbestos-related diseases. At the same time, of course, victims of asbestos are by definition disabled by crippling, progressive lung death for which there is no cure. Therefore because of their deteriorating health they are unable to say with any certainty that they will be fit enough to come in and work from one day to the next. In addition to this, as we understand it, the DSS may shortly begin withdrawing disablement benefits and allowances from asbestos victims should they perform voluntary work. Obviously therefore, since Clydeside Action on Asbestos is a self-help group, should this occur

then we cannot survive.

Our other group of voluntary workers are people who are not themselves victims of asbestos but are sympathetic to their plight. Unfortunately they cannot be relied upon to work since they receive no wages and only the most minimal travelling expenses. If they have the opportunity of taking a real job then they are obliged to take it. It is also the case that restrictions are laid on these non-victim voluntary workers by the DSS.

On the 10th October we convened an Extraordinary General Meeting to inform our membership of the crisis at Clydeside Action on Asbestos, of the increasing victims coming forward in light of the recent publicity, and of the enormous stress placed on members through our never-ending struggle to obtain disability benefits and allowances for asbestos victims. You may be aware that Mr -----, one of our members, collapsed and died during the meeting itself. Mr J-----, another of our members died on the same day.

We had previously informed the Social Works Department of the crisis, that our voluntary organisation can no longer supply welfare rights and support work to asbestos victims. Under existing circumstances we cannot provide an adequate service. The Social Works Department responded by offering to train more volunteer unpaid workers to keep intact some form of service to asbestos victims. At the same time it has been suggested that we may receive limited funding to help offset the financial costs of running the office.

Given that we have no other option, in view of the immediate plight of asbestos victims, we will accept this assistance and ask for more volunteers to come forward.

But until such times as these unpaid victim and non-victim voluntary workers are trained to perform the representation work demanded at MAT's and SSAT's the work cannot be done by this charity. There is no one available or capable of doing it. And in the meantime either the paid workers of the Social Works Department must cope with the problem or else the victims of asbestos will have to live with the reality, that there is no one equipped to assist them.

From here on it is imperative that the MAT, SSAT and DSS services communicate directly with the Social Works Department or else advise the victims of asbestos-related disease that there is no agency available to them, outside of the Citizens' Advice Bureau.

We regret any inconvenience this may cause yourself or your department.

I enclose a copy of the communication we sent in the first to Professor Edwards of Strathclyde Region's Social Works Department advising him of our plight.

At present we remain unable to undertake representation of victims at MAT's and SSAT's. Until a point where the training offered by Professor Edwards will allow our volunteer victim and non-victim workers to set our volunteer workersthis becauseWe no longer have the financial and material resources to deal with the welfare rights' work that we have taken on during past years (almost all of which concerns disablement claims through the DSS). The substance of our communication to Professor Edwards offers a more detailed explanation.

Yours sincerely

8th September, 1992

Professor F Edwards
Social Works Dept
Strathclyde Region
Glasgow

Dear Professor Edwards,

As you may be aware this group received charitable status some twelve months ago. Perhaps due to the present economic climate we have been unable to achieve a degree of financial security in keeping with our new status. Our funding - or lack of it - remains as it was, thus we subsist essentially on the donations made by our own members and sympathisers. Aside from the research gathering and dissemination we engage in, our services include counselling and support work. We campaign on behalf of victims, attempting to monitor and check asbestos abuse. We have no paid staff. Our entire operation is sustained by voluntary workers, 90% of whom are themselves victims of asbestos-related progressive disease.

The fact of the matter is that we cannot continue operating as we do presently and must now reappraise the overall situation in the best interest of the victims. While this is a direct effect of our successful campaigning over the past few months it does not detract from the reality. It is important to stress the situation facing Clydeside Action on Asbestos. Our members die at an average rate of one per week.

The reason I write to you personally is to inform you that we can no longer cope with what has become the most time-consuming part of our work; the counselling service to victims pertaining to disablement entitlements and welfare rights.

For the last few years we have advised and assisted in the preparation of individual claims and appeals relating to industrial disease. As you will be aware there are particular difficulties in handling these claims and appeals in respect to the degree of prerequisite medical knowledge on asbestos-related illness (which is by definition progressive and ultimately terminal). Victims of asbestos experience great problems in obtaining their welfare rights and entitlements through the stringency of the diagnostic procedures (in the West of Scotland the latest figures we have access to, show a rate of failed claims on the prescribed industrial disease, pneumoconiosis (asbestosis) to be a staggering 88%).

Given that we have no professional legal or medical advice, let alone representation, available there remains one obvious reason why victims approach ourselves rather than the Social Works Department for assistance and support in these matters; although a lay-body we do have a body of medical and legal knowledge based upon the direct, personal experience of our members. Our singular awareness of the plight of the victims of asbestos has enabled the group to operate on a 'self help' basis. But the number of victims throughout the West of Scotland now coming forward in search of support and counsel leaves us unable to continue this service. We have had to contact the Medical Appeal Tribunal department at Blythswood House to inform them of the situation.

Yet in the interest of the victims, if we can no longer provide this service we are obliged to ensure that the service can be obtained elsewhere. We have no option but to begin direct referrals then monitor the progress of the individual claims of these victims. Initially, and for the time being, we are fully prepared to provide some form of experiential back-up service to the welfare rights' section within the Region.

The matter has become urgent and we would appreciate that a meeting be arranged between ourselves and an authority from your department at your earliest convenience.

Yours sincerely,

10th November, 1992

Dear Dr. G-----¹,

I apologise for not replying earlier to your letter of 18th September re the posthumous claim of the late Mr J-----². I was off last week when you phoned. The report you read provided the substance of our case at the Medical Appeal Tribunal several weeks ago. Unfortunately the decision went against Mrs. ----- . This was predictable and is why I prepared the report in this way. The next stage in the bureaucracy is an appeal to the Commissioner which can only be done on a point of law. If you have no objections, in our submission I shall refer to the crucial points you mentioned in your letter (which I failed to pick up on originally); it would also be worthwhile to use your name in the context of professional medical authority, if this is at all possible, and I would appreciate an early response from you here since there is a time-bar on Appeals.

I enclose a recent letter in relation to PM's. This advance has only come about through the efforts of our group. No later than four days back we had to fight to obtain both an autopsy and particle count on a man who had been diagnosed mesothelioma but whose death certificate did not register the fact.

Obviously the fight on asbestos is very difficult on many fronts. This is a self-help lay-group of volunteer workers, asbestos victims and sympathetic non-victims. Nobody gets paid. We receive almost no funding and survive from month to month through donations by victims and sympathisers - mainly rank and file members of trades unions. There is no question that much more could be done than we are capable of doing. In the 18 months I've been involved you are the first doctor who has responded in a positive manner (although towards the end of last week I was given the name of a Scottish doctor who has experience in pneumoconiosis via the mining community and has intimated his interest). No lawyer has ever offered practical advice. I've been involved in preparing the cases for Medical Appeal Tribunals for nearly a year and, basically, had to begin from scratch.

When I prepared the report on the posthumous claim for Mrs. Coyle I decided it

¹ Dr Greenberg

² Case number 8

was the last case I would do - if I couldn't assist a family "win a diagnosis" from the medical authorities where the victim is *already* diagnosed mesothelioma by an actual doctor then it was time to change direction. I recommended that we stop doing this kind of work and try other approaches - concentrating on the campaigning side of the work.

This was two months ago. But the back-log of claims has simply built up and the Social Works Department say they can do nothing for the victims aside from train more volunteer workers from our ranks to perform welfare rights' work (I advised them that since 3 to 4 of our victim members die every single month the training programme will have to run forever). We were doing as many as 5 to 7 cases per week and it now looks like we'll be obliged to resume the work since no one else is taking it up; I personally believe it to be a waste of our time and resources but there is no choice.

You spoke to a volunteer who assists with research and he sends the enclosed report he mentioned to you on the phone. I also include other enclosures. In practice every claim is rejected by the DSS and medical authorities at the outset; the asbestos victims then appeal, and thus are obliged to provide the burden of proof that the disease they suffer is asbestos-related.

The battle to obtain diagnosis is regarded by asbestos victims as the most difficult part of the struggle. I have to say that doctors have the same credibility as lawyers in this part of the world and are regarded as integral components of the same conspiracy.

We have won the occasional "victory". Recently we got an appeal upheld at a Social Security Appeal Tribunal on a "prescription question" test-case on a schoolteacher who died of mesothelioma. The DSS are very upset by our "victory" which they recognise could have enormous repercussions throughout the U.K. Therefore, at this minute, the government's medical and legal authorities are searching for the means to have the decision reversed on a point of law in their own Appeal to the Commissioner.

As you might imagine there are many people who offer new ideas to the group; few grasp that we have ideas of our own, it is the attempt to realize these ideas, to consolidate on what we have already achieved, that presents the headaches. Your own response is valued by the group because it is of practical help. We would very much appreciate your continued interest, advice and suggestions.

Although we have long recognised the necessity of professional advice we haven't sought this actively; we're short-handed and there is a mammoth amount of work as things stand already. To be honest, anyone with an interest in asbestos-related disease in Scotland should know of our existence already. My own experience suggests that committed people usually take the trouble to establish contact in the first instance anyway. I enclose a couple of recent media strikes we've made for your background information.

I don't apologise for the fact that my own response to the medical profession is emotional on this issue - a mixture of rage, frustration and contempt, although I'm aware some of this is misplaced. However... and at the risk of presumption, apart from the obvious education on asbestos-induced diseases for the general medical profession, as I see it, some crucial, particular areas of the war on the medical front are

- 1) to press for an increase in the set of prescribed asbestos-related diseases: at present only asbestosis and bilateral diffuse pleural thickening will qualify a victim for welfare entitlements; the prescribed lung cancer category is redundant since it does not exist officially except in the presence of asbestosis or BDPT; the mesothelioma category is as valid as the Coyle case indicates.

- 2) A relaxation of the diagnostic criteria: at the moment only those victims who are at advanced stages in these diseases will qualify (victims with 30 years occupational exposure to the dust are being carted into the DSS Medical Appeal Tribunal complete with oxygen bottles and being asked if they've kept budgies or suffered pneumonia as a boy or if they've stopped smoking etc. or if they actually were exposed to asbestos "at first hand", then of course they're wheeled back out, having failed to "win" their diagnosis, which was a foregone conclusion anyway because radiological "evidence of asbestosis" did not appear).

- 3) An immediate end to the biopsy for suspected asbestos victims (a horror story here relating to metastasis; Clydeside Action has fought for years to stop victims being killed as an effect of it).

- 4) CT scans on the national health (£300 privately at present).

- 5) Adequate care and treatment of victims; this will begin by acknowledging the reality of the insidious nature of these diseases. The term "breathlessness" is used to describe the disabling condition of every asbestos victim (including those suffering mesothelioma) by the adjudicating medical authorities. This must end.

Thereon it will extend to at least showing an interest in the extensive work being done abroad in the treatment of victims. You will appreciate that nobody connected with this group has any illusions; at the same time we receive occasional research from different parts of the world, including Western Australia and the work being done on people native to the Wittenoom region; also we have two mesothelioma male victims on the Moeman diet, one diagnosed a victim for more than two years, the other is Pat McCrystal who was diagnosed back in February and drives his way to the the office at least once per week, he is putting on weight.

The end result of the current medical quagmire is a nightmare in human misery - including premature death as a direct effect of the mental and physical stress required to fight for diagnosis and the resultant basic welfare entitlements. Of course this human tragedy translates into a form of victory for the state, not to mention the asbestos industry, insurance companies, and all those employers who knowingly and intentionally put men and women to work in conditions they knew could poison them and might kill them, not to mention exposing the general public...

However, there we are. I had thought about putting together some sort of lobby style document to send out to chest specialists everywhere bla bla bla. If you have any thoughts on that I'd appreciate hearing them.

All the best

CC (included John Smith MP)

30.9.92

Dear

Please find the enclosed copy of our recent communication to the GMB in Scotland in protest at the treatment of a mesothelioma victim, Mr Pat McCrystal, who is a GMB member of fifty years standing. We feel it to be of the utmost importance that you are brought up to date on the case from us directly (Pat McCrystal is an active member of this group). There is no singular criticism of the GMB procedures here; unfortunately the GMB practice would appear to be the general practice in cases of this nature. The enclosed will provide self explanatory information on Mr. McCrystal's claim and the reasons for his anger and bitterness at the outcome. We are in full support of him in this. We look forward to hearing from you.

Yours sincerely,

Bert Connor
Chairperson.